

MEMO

To: NACHGR

From: Meghan Carey, Executive Director

Date: September 13, 2023

Subject: NSGC Activity Update

Following are key highlights of National Society of Genetic Counselors (NSGC) strategic initiatives and other key activities through early September 2023. If you have questions about information not included in this report, please do not hesitate to contact me at <u>mcarey@nsgc.org</u>. Additionally, we continue to welcome the opportunity for conversation around opportunities for RFAs for Genetic Counseling R01 and R25 grants, the Human Genetics and Genomics Workforce Diversity Initiative, as well as additional conversation around how NSGC can support the NHGRI strategic plan.

NSGC Membership

- As of the end of 2022, NSGC had 4,716 members
- 2023 NSGC membership stands at 4,877 as of August 31; members can join through September 30 for the 2023 membership year.

Board of Directors

- The next in person meeting of the Board is scheduled for October 16, 2023, in conjunction with the NSGC Annual Conference
- The NSGC 2022-2024 strategic plan is available on the <u>NSGC website</u> and outlines the Society's strategic priorities over the next three years
- Strategic planning for 2025-2027 will take place in the summer of 2024, and preliminary planning has started.

Research

- NSGC's top research priorities have been outlined in: <u>Advancing the genetic counseling profession through research:</u> <u>Identification of priorities by the National Society of Genetic Counselors research task force</u>.
- Our Research, Quality and Outcomes Committee is developing recommendations for an infrastructure to advance and support
 patient outcomes research by and about genetic counselors.

Justice, Equity, Diversity, and Inclusion

- Justice, equity, diversity, and inclusion is one of the four strategic areas of focus in our 2022-2024 strategic plan.
- The Exeter Group led an NSGC J.E.D.I. Action Planning Task Force to develop an implementation plan for the
 recommendations that will be integrated into the 2022-2024 strategic plan. The Action Plan has been finalized and is available
 here.
- Action Plan implementation is underway.
- We have been in dialogue with ASHG and other organizations as we develop our action plan to ensure our organizational efforts align with and contribute to increasing diversity and inclusion in the broader genetics and genomics workforce, and support extending the reach of genetics and genomics into underserved patient populations.
- We would welcome a dialogue with NHGRI to align and collaborate with other genetics workforce diversity initiatives as our efforts move forward.

Education and Publications

• NSGC is approved as a provider of Continuing Education Units (CEUs) for genetic counselors. Please contact <u>Grant</u> <u>Whittaker</u>, NSGC Continuing Education Coordinator, with any questions.



- The 2023 NSGC Annual Conference will be held October 17-21, 2023, in Chicago, Illinois. In order to increase
 accessibility for all interested attendees, the conference will be held in a hybrid format with sessions available both inperson and online. Information is available on the <u>NSGC website</u>.
- NSGC has many online educational opportunities available for additional continuing education. These cover a variety of topics such as family history, coding and billing and cultural competence. Additional information on these and other courses is available to the public on the <u>NSGC Online Education Center</u>.
- Recordings of all sessions from the 2021 and 2022 Annual Conference are <u>available online</u>.

Liaison Activities

- NSGC Past President Joy Larsen Haidle is serving as NSGC's representative on the American Society of Clinical Oncology's (ASCO) CancerLinQ Oncology Leadership Council.
- Rachel Mills represents NSGC on the Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC).
- Barbara Bernhardt is serving as the NSGC liaison to the "value of genetic diagnosis" committee led by Marc Williams from ACMG.
- Cate Walsh Vockley represents NSGC on the HRSA Advisory Committee on Heritable Disorders in Newborns and Children Subcommittee (ACHDNC).
- Past President Cathy Wicklund represents NSGC on the National Academies of Medicine Roundtable on Genomics and Precision Health.
- Ashley Parrot is representing NSGC as liaison to the ACMG Practice Guidelines Committee.
- Maria Baker is serving as liaison to the American College of Surgeons Commission on Cancer (CoC).
- Megan Frone is representing NSGC in the National Accreditation Program for Breast Centers (NAPBC).
- Brian Reys is NSGC's representative to the AMA CPT/Health Care Professional Advisory Committee Council.
- Rhonda Schonberg is transitioning off as NSGC's representative to the National Advisory Council for Human Genome Research (NACHGR) and will be replaced by Leila Jamal.
- Alix D'Angelo is representing NSGC on the Training Residents in Genetics (TRIG) Committee. The TRIG committee
 is comprised of representatives from pathology and genetics organizations and is focused on ensuring genetics is
 included in future training of pathology residents.
- Kristin Vogel Postula is representing NSGC as a member of the American Association of Oncology Nurse Navigators (AONN+) Advisory Committee.
- NSGC Past President Karin Dent represents NSGC as a member of the Genetics in Primary Care Institute, an initiative of the American Academy of Pediatrics.
- Heather Hampel is representing NSGC as a member of the National Colorectal Cancer Roundtable (NCCRT).
- Sarah Kalia is serving as NSGC's representative to the ACMG Incidental Findings Working Group.
- Allison Cirino represents NSGC as liaison to the Functional Genomics and Translational Biology (FGTB) Council of the American Heart Association.
- NSGC Past President Angie Trepanier and Meg Doerr represent NSGC on the G2C2 Committee.
- Kelly Knickelbein represents NSGC on the Cancer Precision Medicine Commons, the follow-up project to the Consistent Testing Terminology Working Group coordinated by LUNGevity and involving other patient advocacy groups, societies and industry.
- Karen Wain is serving as NSGC representative to the Association for Molecular Pathology Clinical Whole Exome Sequencing for Inherited Conditions as a First-Line Test: Spectrum of Applications and Standards

Government Relations and Advocacy

• Several NSGC position statements are in development or revision. All NSGC position statements are available on the <u>NSGC website</u>.



- NSGC is pursuing legislation that will recognize genetic counselors as Medicare providers, the Access to Genetic Counselor Services Act. Organizations interested in supporting this legislation can learn more <u>here</u>.
- NSGC is providing ongoing guidance to states pursuing licensure and writing licensure rules and regulations:
 - Issuing licenses: AL, AK, CA, CT, DE, FL, GA, ID, IL, IN, IA, KY, LA, MA, MI, MN, MT, NE, NH, NJ, NM, ND, OH, OK, OR, PA, RI, SD, TN, UT, VA, WA, Wi
 - Passed bills/in rulemaking: HI, MD
 - o Most remaining states have bills introduced or in preparation